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PREDICTORS OF SURROGATE INVOLVEMENT IN ADVANCE CARE
PLANNING BEHAVIORS

BY

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A THESIS SUBMITTED IN PARTIAL FULLFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN PSYCHOLOGY

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Abstract

Advance care planning (ACP) is a framework used to describe the process of end-of-life care planning. ACP includes four behaviors: completing a living will that documents end-of-life wishes, appointing a health care proxy (HCP), discussing the use of interventions with loved ones, and discussing quality versus quantity of life with loved ones. Studies have found that the number of individuals engaging in ACP is low. Further, even those who have completed a living will and HCP often have insufficient communication with loved ones regarding their end-of-life wishes, often leading to discordant end-of-life care. The present study used constructs from the Transtheoretical Model (TTM) to examine predictors associated with surrogates' ($N=216$) readiness (i.e., Stage of Change) to help their loved one complete ACP behaviors. Exploratory analyses including Analyses of Variance (ANOVAs) and correlations examined surrogate age, race, gender, experience with medical decision making relationship to the older patient, frequency of contact, perceived positive consequences of ACP behaviors (Pros), perceived negative consequence of ACP behaviors (Cons), and ACP attitudes values and cultural beliefs (AVCB) as potential predictors of surrogate readiness to assist their loved one in the four ACP behaviors. A series of multiple regressions showed that across the four ACP behaviors, only Cons was a significant predictor of Stage of Change, suggesting that as surrogates perceived more negative consequences of ACP, they were less ready to support the older patient in the process. This result is not consistent with other TTM research, in which Pros and Self Efficacy are generally stronger predictors of Stage of Change. This study also examines the level of agreement between older patients and their surrogates on readiness to engage in the four ACP behaviors. Difference scores between the

surrogate Stages of Change and that of their older patient counterpart reflected discrepancies in readiness for ACP behaviors. ANOVAs and correlations were used to examine relationships between the level of agreement and the surrogate variables. Stage of Change distributions revealed surrogates were more ready to participate in ACP behaviors than the older patients, indicating that surrogates may play an important role in older patients' readiness to complete ACP behaviors. Increased surrogate age was associated with less agreement on readiness to engage in creating a living will. Female gender and higher surrogate ratings on Pros was associated with more agreement in discussing interventions. Higher surrogate ratings of Cons was significantly associated with less agreement to discuss interventions, and more agreement to discuss quality versus quantity of life. Higher ratings on AVCB was significantly associated with less agreement in readiness to discuss interventions. Future longitudinal research may provide more information regarding these relationships.

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Introduction

Current medical interventions, such as the use of life-sustaining machines, have the potential to prolong life far beyond the point at which an individual would live in the absence of these interventions. The use of these interventions often results in end-of-life care that is costly and exceeds the amount and duration of medical interventions the patient wished to receive (Zhang, 2009). Thus our intervention driven medical culture tends to put patients, their physicians, and their loved ones in a position of extending quantity of life at the expense of quality of life. Therefore, it is important for all involved in end-of-life care to consider the costs and benefits of life sustaining medical technologies. Research suggests that fewer life sustaining interventions could lead to better end-of-life outcomes. For example, Cohen et al. (2011) analyzed 701 retrospective reports from physicians of deceased patients in Brussels, Belgium and found that overall, patients who received palliative care services (i.e. services that aim to allay discomfort at end-of-life rather than attempting to prolong life) had greater feelings of well-being as measured by the Edmonton Symptom Assessment System (ESAS) as well as less shortness of breath, implying that they experienced less anxiety than those who did not receive palliative care. In addition, it was found that patients who received palliative care were more likely to die in the setting they preferred (i.e. mostly within the home) than those who did not receive palliative care (Cohen et al., 2011). These findings suggest that patients who received palliative care were more likely to have their preferences followed at end-of-life care. In order to receive the desired form of end-of-life care, the patient must explicitly make their wishes known to their loved ones and physician. The appropriate

steps that are taken to accomplish this include the following: creating a living will (a document that includes end-of-life care wishes), and appointing a healthcare proxy (HCP), a patient advocate who ensures that physicians adhere to patient wishes. This process is described as Advance Care Planning (ACP), in which a patient can prepare for a time that they may be unable to communicate their healthcare preferences regarding the utilization of life-prolonging machines and procedures or palliative care. A recent study that examined the need for ACP in medical settings found that out of 1083 hospitalized older patients, up to 57.2% required medical decision making by a surrogate and only 7.4% of the sample had a living will and 25% had an HCP document in their medical record (Torke et al., 2014). These findings highlight the current need for ACP completion in older patient populations.

ACP is best not thought of as a static process in which one's preferences remain constant throughout changing circumstances. It is important for all involved in the process to understand the older patient's preferences as they may shift and evolve, which requires adequate and continuous communication. Current research suggests that poor communication between a patient, their physician, and loved ones (i.e. surrogates) regarding end-of-life care typically results in care that is discordant with patient wishes (Swetz, Kuczewski, & Mueller, 2011). Therefore, in addition to completing documentation, the patient continuing to communicate their wishes to physicians and loved ones should improve the likelihood that they will receive the end-of-life care they desire (Hines, Toale, Heisel, & Baringer, 2000; Swetz et al., 2011). In addition to creating a living will and HCP, communication between the

patient and surrogate, as well as communication between the patient and physician has been regarded as an important component of ACP (Fried et al., 2010).

Justification and Significance of the Study

The current literature on ACP and quality-of-life (QOL) ratings is mainly concerned with agreement between the patient and their HCP regarding end-of-life preferences (Capelle, Vlak, Algra, & Rinkel, 2010; Essen, 2004; Fried et al., 2011; Hawkins, Ditto, Danks, & Smucker, 2005; Hines et al., 2000; Jette et al., 2012; Parks et al., 2011; Rothman et al., 1991; Seckler, Meier, Mulvihill, & Paris, 1991; Shalowitz, Garrett-Mayer, & Wendler, 2006; Swetz et al., 2011; Winters & Parks, 2008). This research found that while surrogate ratings of patient QOL and physical ability (e.g. ambulatory abilities) are reasonably accurate, surrogate-patient agreement on advance care preferences is poor. It appears that surrogates have better understanding of their loved one's physical health rather than their preferences for treatment at end-of-life care. Further, while ACP improves end-of-life care outcomes for patients and their families, communication regarding this process between patients and their surrogates and physicians is lacking (Patel, Janssen, & Curtis, 2011). Thus, research is needed in order to understand factors associated with the level of surrogate involvement in ACP for a loved one.

Currently, no research specifically examines factors that potentially predict surrogates' readiness to assist a loved one in ACP. The present study attempts to address this question by using Multiple Regression modeling to assess whether demographics (i.e. age, race, gender, and relationship to older patient), frequency of interaction with the older patient, medical experiences, and Pros and Cons can

adequately predict readiness to assist an older patient in ACP. In addition, these predictors of surrogate readiness to help an older patient will be analyzed as predictors of agreement between the surrogates and their loved ones on readiness to complete (older patient) or assist (surrogate) in completion of ACP behaviors. In the present study, agreement is defined as the level of discrepancy between older patient-surrogate readiness to complete (i.e., Stage of Change) in the ACP behaviors. Previous analysis on these data showed that agreement between older patients and surrogates on completion of a living will document was high (81%), while agreement on the other ACP behaviors were fair to poor: completion of a healthcare proxy (68%), communication regarding the older patient's views on life-sustaining treatment (64%), and communication regarding quality versus quantity of life (62%) (Fried, Redding, Robbins, O'Leary, & Iannone, 2011). These findings are limited in that they were assessed from 'yes'/'no' answers; thus, analyzing the predictors associated with these findings on agreement would add depth and clarity to understanding of the surrogate role in ACP.

Research suggests there are gaps in surrogate understanding of their loved one's end-of-life wishes that can be addressed with effective communication. Insufficient surrogate-patient communication can lead to multiple problems in end-of-life care. Studies have shown that physician decision making when the patient is unable to communicate near end-of-life results in care that is typically discordant with patient wishes (Shalowitz et al., 2006; Torke, Moloney, Siegler, Abalos, & Alexander, 2010). Although physicians typically express that they view patient preferences as important, there is evidence that suggests the presence of a living will, patient-physician

discussions regarding end-of-life treatment, and physicians' personal beliefs on the subject do not significantly predict physician adherence to patient preferences (Torke et al., 2010). Given that physicians will typically act in favor of aggressive medical care (e.g. the use of life sustaining procedures) regardless of whether it adheres to patient wishes, it is important that the patient have a surrogate present to ensure that care is concordant with the patient's wishes. In summary, although surrogate decision making is also imperfect, physician decision making in end-of-life treatment is often more discordant with patient preferences (Shalowitz et al., 2006).

Even in the event that a surrogate is present, decisions made by surrogates are often inaccurate due to insufficient communication between the patient and the surrogate as well as overconfidence in both the patients and surrogates regarding surrogate decision-making accuracy (Hawkins et al., 2005; Hines et al., 2000; Shalowitz et al., 2006; Swetz et al. 2011). Although living will documents are an important component in ACP, designations are often rigid and can be difficult to interpret in ambiguous situations. For example, Mahon (2011) explains that a patient may consider a treatment if it will improve health, but may refuse the same treatment if it will prolong life at the expense of QOL. A surrogate who can accurately report the patient's wishes would be essential in this circumstance. Moreover, research suggests that patients' advance care preferences change significantly overtime, corresponding with changes in health and perspectives regarding quality versus quantity of life (Fried et al., 2007). Evidence suggesting that ACP is a dynamic process, further emphasizes the importance of effective and continuous surrogate-patient communication.

Although research on the effects of improved communication on ACP readiness is limited, the extant literature suggests that when patient-surrogate communication is sufficient, surrogate involvement in the process of ACP can improve understanding of patient end-of-life care preferences and improve adherence to the patient's wishes, thus allaying some of the stress and burden associated with difficult medical decision making that is experienced by all involved. The current literature on ACP supports the argument that older patient-surrogate communication is as important in ACP as completing a living will and HCP (Hines, et al., 2000; Shalowitz et al., 2006; Swetz et al., 2011; Torke, et al., 2010). In the present study, communication regarding the use of life sustaining interventions and communication regarding quality versus quantity of life are included as two behaviors that are relevant to ACP. In summary, communication plays an important role in ACP and the present study attempts to examine this factor by assessing a frequency of contact measure as a predictor of surrogate readiness to assist their loved one in ACP and agreement in Stage of Change of the four ACP behaviors (i.e. creating a living will, creating a HCP, communicating preferences regarding the use of life sustaining treatments, and communication regarding quality versus quantity of life).

Programs aimed at raising awareness of the importance of ACP in patients nearing end-of-life can improve quality of death by ensuring that patients' medical wishes are followed (Fried et al., 2012; Levy, Morris, & Kramer, 2008). However, older patients often approach end-of-life without ensuring that their advance care wishes are known through a living will or advance directive, a HCP, or through adequate communication with surrogates and physicians. Although patients often view ACP in a positive light,

rates of completion of living wills and HCP are low (Salmond & Estrella, 2005; Silveira, Kim, & Langa, 2010). More specifically, Silveira et al. (2010) reviewed medical records of 3746 subjects (≥ 60 -years-old) and found that individuals who completed a living will were more likely to request limited care and those who completed a HCP were more likely to die outside of the hospital. Further, patients who did not complete a living will or HCP were more likely to receive aggressive care at end-of-life in a hospital. In summary, older patients who do not make their wishes known by completing ACP and communicating their wishes to physicians and loved ones could potentially receive end-of-life care that is more aggressive than they might prefer. This information highlights the importance of understanding factors associated with successful completion of ACP. More importantly, with completion rates of ACP being unacceptably low (Silveira et al., 2010, Torke et al., 2014), surrogate aid in the process of completing a living will and HCP could improve end-of-life care outcomes. Therefore, it is important that the present study examine factors that could serve as predictors of surrogate readiness to assist an older patient in completing a living will and HCP.

Transtheoretical Model

The Transtheoretical model (TTM) is a comprehensive and integrative model of behavior change that has been applied as an organizing framework to understand behavior change and decision-making in dozens of contexts (Prochaska et al., 1994). The following key constructs are included in the TTM: Stages of Change, Decisional Balance, Self-efficacy and Processes of Change. The Stages of Change construct is based on a series of stages that individuals tend to move through in efforts to achieve

behavior change (Prochaska et al., 1994). The Decisional Balance construct was adapted from Janis and Mann's (1977) decision making model. This construct is essentially a decisional balance checklist of comparative gains (Pros) and losses (Cons) (Prochaska et al., 1994). The Self Efficacy construct was derived from Bandura (1977) and this term refers to an individual's confidence in their ability to complete a behavior. The Processes of Change construct is aimed to examine behaviors that represent activities that people use to progress through the Stages of Change; these include experiential and cognitive processes (e.g. consciousness raising and self-reevaluation), which are used in the earlier stages, and behavioral processes (e.g. helping relationships and self-liberation), which are used in later stages (Fried et al. 2010). The TTM has shown consistent results when applied to 48 different health behaviors in 10 different countries (Hall and Rossi, 2008), indicating that the TTM is generalizable as a model for behavior change across many different groups. Moreover, the TTM Stages of Change have been used as a conceptual framework for social workers discussing advance care planning with patients that had advanced illnesses (Rizzo et al., 2010).

Fried and colleagues (2012) were the first to develop and validate scales that measure the TTM constructs as applied to ACP behaviors in a sample of older patients. In the present study, two key constructs of the TTM will be analyzed: Decisional Balance and Stage of Change. The Stages of Change range from a stage that indicates that a participant is not considering changing a behavior to a stage that indicates the participant has performed the behavior more than 6 months prior. Precontemplation defines the stage in which an individual is not planning on changing

a behavior in the foreseeable future (i.e. within the next 6 months). Contemplation is the stage that indicates an individual is planning to take steps toward behavior change in the next 6 months. Preparation is characterized by an individual planning to change a behavior in the more immediate future (i.e. within the next 30 days). Action is the stage that indicates an individual has made behavior changes within the preceding 6 months. Maintenance is a stage that indicates an individual is continuing the desired behavior; in the context of the present study, Maintenance describes an individual who completed ACP documentation and communicated their preferences to surrogates prior to 6 months (Fried et al., 2010). The Decisional Balance construct (Pros and Cons) is an intermediate indicator of change, meaning that there is a consistent relationship between the level of Pros and Cons and Stage of Change: as individuals progress from Precontemplation to action, the maximum increase in Pros is typically twice the maximum decrease in Cons (Hall and Rossi, 2008).

Given that TTM constructs have shown consistent results across many different behaviors, including the context of ACP (Fried et al., 2012), this model of behavior change would be an appropriate framework for understanding readiness to complete ACP behaviors. In the present study, the (TTM) Stages of Change were used in the surrogate sample to assess readiness to help an older patient in ACP (Fried et al., 2010). Based on questions regarding thoughts on ACP completion behaviors, participants were placed into their respective Stage of Change (i.e. Precontemplation, Contemplation, Preparation, Action/Maintenance). Surrogates were also asked a series of questions regarding the Pros and Cons of helping a loved one complete ACP.

Predictors of Surrogate Stage of Change

Based on previous findings, several independent variables can be tested as predictors of Stage of Change for each of the four ACP behaviors in the present study.

Surrogate Age and Gender. Evidence suggesting that age and gender play a role in surrogate ACP involvement is scarce. However, Hines and colleagues (2000) found that of the patients who chose a parent as surrogate, mothers were chosen significantly more often (78%) than fathers (22%). Additionally, although the gender differences in other categories (i.e. spouse, child, sibling, and friend) were not significant, the overall frequency of females in the Hines et al. (2000) study was higher than males. The greater frequency of female surrogates might suggest that females in the present study will be more likely to be at a later stage of readiness for ACP than males. In addition, Alano and colleagues (2010) examined predictors associated with completion of advance directives in a sample of older adults (> 65-years-old) and found that significantly more females completed advance directives than males. Although this finding is not derived from a surrogate sample, it suggests the likelihood that females will participate in ACP is higher than males. It was also found that increased age was a predictor of completion of an advance directive (Alano et al., 2010). For example, participants that were above age 85 were 6.3 times more likely to complete an advance directive than participants 59-75 years old. These results suggest that increased age in the surrogate sample may be associated with greater likelihood of being at a later Stage of Change to assist a loved one in ACP.

Surrogate Race. It is expected that race will be a significant predictor of Stage of Change in each of the four ACP behaviors. More specifically, Whites will have

greater likelihood of being in a later Stage of Change than Nonwhites. Hopp & Duffy (2000) used logistic regression to compare differences in ACP and end-of-life care decision making amongst Whites and Blacks. Results from this study showed that Whites were significantly more likely to discuss ACP with loved ones, complete a living will, and appoint a HCP. In addition, Fried and colleagues (2010) found that, in a sample of old patients (≥ 65 -years-old), the majority of Whites were in the Action/Maintenance Stage of Change (54%), while the majority of Nonwhites were in the Precontemplation Stage of Change (59%). These findings suggests that the likelihood of White surrogates discussing ACP and assisting older patients in the planning process will be higher than Nonwhites in this study.

Surrogate-Older Patient Relationship. Research comparing the accuracy of surrogates with different relationships to the older patient, specifically between children and spouses, found that spouses are more likely to be chosen as a HCP and are significantly more accurate than children in following patient preferences at end-of-life (Parks et al., 2011). Although there is currently no research specifically comparing spouse and child readiness to assist in the ACP process, evidence was found that the frequency of spouses serving as surrogates was significantly greater (55%) than adult children (23%) (Hines et al., 2000). These findings suggest that in the present study, it is likely that spouses will be at a later Stage of Change for ACP behaviors than children of older participants.

Surrogate-Older Patient Communication. The literature on ACP suggests that communication is a key component of surrogate accuracy and comfort with the topic (Fried & O'Leary, 2008; Hines et al., 2000; Lang & Quill, 2004). This research

implies that surrogates who have nuanced understanding of the older patient's end-of-life wishes will be more willing to assist that person in ACP. It is expected that surrogates who communicate more often with their loved one will have greater likelihood of being involved with assisting the older patient in each of the four ACP behaviors.

Surrogate Life Experience with Medical Decisions. Medical experiences might serve as predictors of readiness to assist a loved one in ACP. Previous research has identified that experience of major surgery makes old adults' completion of advance directives six times more likely to occur (Alano et al., 2010), suggesting that surrogates with more medical experiences in the present study will have greater likelihood of being at a later Stage of Change in readiness to assist in ACP. Further, in a study assessing factors that help or hamper surrogates' willingness to assist an older loved one in ACP found that previous experience with medical decision making is a factor that helps surrogates in this process (Vig et al., 2007).

Surrogate Pros and Cons. It is expected that endorsements in the Decisional Balance construct of the TTM will serve as predictors of Stage of Change. More specifically, previous research examining the validity and reliability of the TTM in ACP behavior change on a sample of older adults (≥ 65 -years-old), found that an increase in Pros and a decrease in Cons of ACP was associated with increased readiness in ACP participation (Fried et al., 2012). It is expected that results from the present study will be consistent with results from the Fried and colleagues (2012) study in that increased Pros and decreased Cons will be associated with later Stages of Change (i.e. greater readiness to help a loved one in ACP behaviors).

Surrogate Attitudes Values and Cultural Beliefs (AVCB). Medical misconceptions as well as religious beliefs that regard a higher power as the entity that determines health outcomes have been shown to influence medical decision making, particularly in the context of organ donation and ACP. In a review examining the cultural influences on African American's willingness to become an organ donor, Morgan (2006) highlights the common medical misconceptions and religious beliefs that influence the decision to become an organ donor. The view that physicians will not save the lives of those who declare themselves as organ donors is a common medical belief that discourages organ donation in African Americans. Further, religiosity can influence the decision to donate organs in two ways: religious leaders might not emphasize the importance of certain health behaviors, and religious myths might discourage certain health behaviors (Morgan, 2006). Similar misconceptions have also been found to deter blood donation (Burditt et al., 2009). Given that medical mistrust and misconceptions seem to be a barrier to health care planning, Fried and colleagues (2012) developed the ACP Values and Beliefs scale (AVCB) that will be analyzed in the present study. This scale includes items that inquire about the misconceptions and attitudes that might deter individuals from completing ACP. Fried and colleagues (2012) found that in a sample of 304 older patients, ACP values and beliefs are significantly associated with Stages of Change, which measure readiness to complete all ACP behaviors. Given these previous findings, it is reasonable to predict that this scale will show similar associations to Stages of Change in the surrogate sample.

Surrogate-Older Patient Discrepancy on Stage of Change

In addition to examining predictors of surrogate Stage of Change in each ACP behavior, the present research aims to examine factors associated with surrogate-older patient discrepancy. This set of analyses will describe the nature of the relationships between variables including surrogate age, gender, race, relationship with the older patient (Relationship), frequency of contact with the loved one (Communication), experiences with medical decision making (Life Experience), Pros, Cons, AVCB, and surrogate-older patient discrepancy on Stage of Change in each of the four ACP behaviors.

Hypotheses

The present study attempts to further understand the factors associated with surrogate involvement in ACP by examining potential predictors of surrogate readiness to assist a loved one in ACP behaviors as well as better understanding the relationships between surrogate-older patient discrepancies on the level of readiness for completion of ACP behaviors and the predictor variables. ANOVAs and Chi-square tests will be used as exploratory analyses to test group differences between the predictor variables and Stage of Change as well as the surrogate-older patient discrepancy on Stage of Change in each of the four ACP behaviors. Multiple Regression analyses will be used to assess whether variables such as age, race, gender, Relationship, Communication, Life Experience, Pros and Cons, and AVCB, can predict surrogate readiness to assist a loved one in ACP behaviors. The following hypotheses will be tested:

1. Predictors of surrogate readiness to assist a loved one (i.e. Stage of Change) in each of the four ACP behaviors will include the following: a spousal relationship to the older patient, interacting with the older patient daily, White race, female gender, increased age, greater experience with medical decision making, increased Pros, and less religious and medical misconceptions related to end-of-life care.
2. Exploratory analyses will be run in order to elucidate the relationship between the surrogate variables, which include age, gender, race, Relationship, Communication, Life Experience, Pros, Cons, and AVCB, and the surrogate-older patient Discrepancy variable.

Methods

Participants and Recruitment

Data for the present study were collected from 218 older patients and their surrogate, who was identified by the older patient, from two primary care facilities and one senior center. Older patients in this study were screened by physicians as not having a diagnosis of dementia. Trained interviewers conducted in-person interviews with the older patients, as well as phone interviews with the surrogates. Of note, while a total of 304 older patients participated in this study, roughly two thirds of this sample identified a surrogate who subsequently agreed to participation. In addition, the majority (i.e. approximately two thirds) of the older patients who identified surrogates were in the Action/Maintenance Stage of Change across the four ACP behaviors.

Measures

The following measures were developed by Fried and colleagues (2010).

Although these measures were tailored for administration to the respective samples, they were only validated in the older patient sample; not the surrogate sample (Fried et al. 2010, 2012).

Descriptive Information. Demographic information was collected, which includes age, race, gender, and the relationship with the older patient (i.e. Child, Spouse, Significant other, or Other relationship). In addition, surrogates reported the frequency of contact with the older patient as a proxy measure for the amount of older patient-surrogate communication.

Surrogate Age and Gender. The older patients had a mean age of 75 ($SD = \pm 7$) and the majority of the older patient sample were female (73%). The surrogate sample had a mean age of 60 ($SD = \pm 12.7$) and were also majority female (68%).

Surrogate Race. The majority of the older patients were White (74%). Surrogates endorsed one of three different racial/ethnic categories: White, Black, and Other race. Sixty-nine percent of the sample identified as White, 26% identified as Black, and 5% identified as Other race. Given that the Other race category made up a small portion of the sample, race was dichotomized into White and Nonwhite categories. After dichotomizing this variable, Whites made up 69% of the surrogate sample ($N = 151$), and Nonwhites made up 31% ($N = 67$).

Surrogate-Older Patient Relationship. Surrogates endorsed one of five different relationships to the older patient categories: Child (42%), Spouse (40%), Significant other (1%), Other relative (12%), and Other (5%). For analysis purposes,

these categories were collapsed into three groups: Child, Spouse and Other. Other relative and Significant other categories represented a small percentage of the sample (6%); therefore, it was determined that collapsing these categories with the Other relative category would be appropriate. After categorizing relationships into three groups, spouses made up 40% of the sample (N= 88), children made up 42% (N= 92), and other relationships made up 18% (N= 38).

Surrogate-Older Patient Communication. Surrogates endorsed one of three different frequency of contact (with the older patient) categories: Daily (76%), Weekly (19%), and Less than weekly (4%). Given that those surrogates who contacted the older patient less than weekly only made up 4% of the sample, the frequency of contact categories were dichotomized into Daily and Weekly or less. Surrogates who had daily contact with the older patient constituted 76% of the sample (N= 167) and 24% of the sample (N=51) contacted the older patient weekly or less.

The goal for collapsing the above described independent variable categories is to address limitations in sample size in some participant subgroups and to improve the statistical power of the analyses. Table 1 presents the demographic information of the older patient and surrogate samples.

Surrogate Life Experience with Medical Decisions. A series of six questions was used to assess surrogates' prior experiences with medical experiences and decision making. The surrogates were asked if they have experienced medical problems themselves or if they have witnessed others experience medical problems or had to make difficult medical decisions for others. The Life Experience index includes items such as, "Have you ever faced a life-threatening illness?" and "Have you ever

had to make a medical decision for someone who was dying?” Participants were asked to respond ‘Yes’ or ‘No’ to each item. See Appendix A for a complete list of the Life Experience items. These items were not formally developed as a scale and as such internal consistency was modest ($\alpha = .48$). The items were summed and treated as an index and used as a predictor variable for the present analyses.

Older Patient Stage of Change. The ACP behaviors assessed in the older patient sample are similar to those assessed in the surrogate sample. The four ACP behaviors assessed in the older patient sample include the following: creating a living will (Living Will), creating a Health Care Proxy (HCP), talking to friends and family about end-of-life care interventions (Interventions), and talking to friends and family about quality versus quantity of life (Quality vs. Quantity of Life). A Stage of Change algorithm, similar to the above described algorithm for the surrogate sample, was defined for each ACP behavior and older patients rated their readiness to complete each of the four behaviors. Table 2 includes the frequencies of Stage of Change in the surrogate and older patient samples as well as the difference between the percentage of surrogates and older patients in each Stage of Change within the four ACP behaviors.

Surrogate Stage of Change. While the assessments of readiness to complete ACP behaviors in the older patients focus on their own readiness to complete the ACP behaviors, the surrogates are asked about their readiness to assist an older patient in completing the four behaviors. A Stage of Change algorithm was defined for each ACP behavior and surrogates rated their readiness to help the loved one in creating a living will (Living Will), help the loved one in creating a Health Care Proxy (HCP), talk to the loved one about end-of-life care interventions (Interventions), and talk to

the loved one about quality versus quantity of life (Quality vs. Quantity of Life). For each algorithm, surrogates rated their readiness on a four point scale from 1=Precontemplation (e.g., I am not ready), 2=Contemplation (e.g., I am thinking about helping/talking to my loved one in the next 6 months), 3=Preparation (e.g., I am planning on helping/talking to my loved one in the next 30 days), or 4=Action/Maintenance (e.g., I have helped/talked to my loved one within the past 6 months or more.) See Appendix D for the measure that assessed participants' Stage of Change for each ACP behavior in the surrogate sample.

Surrogate-Older Patient Discrepancy on Stage of Change. The level of discrepancy between the Stage of Change of the older patient and their surrogate was determined by subtracting the surrogate Stage of Change from the older patient Stage of Change; thus, 0 indicates no discrepancy (Optimal Agreement), 1 indicates (Good Agreement), 2 indicates (Low Agreement) and 3 indicates the highest level of discrepancy (No Agreement). This measure only reveals the level of surrogate-older patient discrepancy on Stages of Change; not the nature of the discrepancy. For example, a surrogate-older patient pair could show Optimal Agreement in an ACP behavior if both are in the Precontemplation Stage of Change or if both are in the Action/Maintenance Stage of Change. A discrepancy (i.e. a value of 1, 2, or 3) shows the level of discordance between the surrogate and older patient on their readiness to complete a given ACP behavior, but it does not describe which participant (i.e. the surrogate or the older patient) is in each Stage of Change. Discrepancy will be analyzed as a continuous measure. Table 3 provides descriptive statistics for

Discrepancy in surrogate-older patient Stage of Change in each of the four ACP behaviors.

Surrogate Decisional Balance (Pros and Cons). The Decisional Balance measure included 6 Pros (i.e., the perceived benefits) and 6 Cons (i.e. the perceived limitations) of assisting a loved one in ACP. These items were rated on a 5 point scale from 1="Strongly Agree" to 5="Strongly Disagree". Items are listed in Appendix B. This sample indicated good reliability for Pros ($\alpha=.88$) and Cons ($\alpha=.84$).

Surrogate AVCB. The AVCB measure includes 7 items that assess religious beliefs and medical myths associated with ACP. Surrogates endorsed these items on a 5-point scale assessing the level of agreement with each statement with 1 representing 'Strongly Agree' and 5 'Strongly Disagree.' Chronbach's alpha indicates good internal consistency ($\alpha=.86$). The AVCB items include "My loved one does not need to do advance care planning because once you reach a certain age, the doctors aren't going to use machines," and "My loved one does not need to do advance care planning because once it becomes clear that you are dying, the doctors aren't going to use machines." See Appendix C for the AVCB items. Table 4 includes the Chronbach's alphas for Life Experiences, Pros, Cons, and AVCB. Correlations amongst these measures can be found in Table 5. Figure 1 illustrates the distribution of surrogate ratings of Pros, Cons, and AVCB across Stages of Change in each of the four ACP behaviors.

Hypothesis I: Predictors of Surrogate Stage of Change

Methods

For exploratory analyses, a series of one-way ANOVAs were used to compare older patients to surrogates on the continuous variables, which include age, Life Experience, Pros, Cons, and AVCB, by Stage of Change for each of the four ACP algorithms: Living Will, HCP, Interventions, and Quality vs. Quantity of Life. A series of chi-square tests compared the older patients to surrogates for categorical variables, which include race, gender, Relationship, and Communication, by Stage of Change for each of the four ACP algorithms. Variables that showed significant group differences across Stage of Change in any of the four ACP behaviors were entered into the Multiple Regressions analyses. All statistics were run using IBM SPSS Statistics version 20.

Results

Exploratory Analyses.

Living Will. Significant group differences among the Stages of Change for creating a Living Will, were found for Pros $F(3, 209) = 8.99, p < .001, \eta^2 = .114$. Post hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M = 39.79, SD = 9.34$) rated the Pros as significantly less important than those in Preparation ($M = 53.33, SD = 8.61$) and Action/Maintenance ($M = 50.96, SD = 9.81$), both $p < .001$. In addition, participants in Contemplation ($M = 46.99, SD = 9.41$) rated Pros significantly lower than those in Preparation, $p = .024$.

Significant differences among Stages of Change were found in Cons $F(3, 194) = 22.13, p < .001, \eta^2 = .225$. Post hoc analyses using Tukey HSD tests indicated

that participants in Precontemplation ($M= 64.85$, $SD= 8.07$) rated the Cons significantly as more important than those in Preparation ($M= 48.27$, $SD= 9.61$) and Action/Maintenance ($M= 47.21$, $SD= 8.02$), both $p< .001$. In addition, participants in Contemplation ($M= 57.07$, $SD= 10.14$) rated Cons significantly higher than those in Preparation and Action/Maintenance, both $p< .001$.

Significant differences among Stages of Change were found for AVCB $F(3, 194)= 3.34$, $p=.02$, $\eta^2= .049$. Post Hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 57.71$, $SD= 7.33$) endorsed a significantly higher level of concerns and myths about ACP than those in Preparation ($M= 48.91$, $SD= 10.26$), $p= .046$, and Action/Maintenance ($M= 49.11$, $SD= 9.80$), $p= .031$. Table 6 shows the ANOVA results for surrogate ratings on Pros, Cons, and AVCB by Stage of Change for the Living Will behavior.

No significant group differences among Stages of Change for creating a living will were found on age, race, gender, Relationship, Communication, and Life Experience.

HCP. Significant group differences among Stages of Change for naming a HCP, were found for Pros $F(3, 209)= 4.83$, $p=.003$, $\eta^2= .065$. Post hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 38.18$, $SD= 8.41$) rated Pros significantly lower than those in Contemplation ($M= 49.15$, $SD= 8.28$), $p= .020$, Preparation ($M= 50.85$, $SD= 9.15$), $p=.003$, and Action/Maintenance ($M= 50.85$, $SD= 10.35$), $p=.001$. Table 7 presents the ANOVA results for surrogate ratings on Pros and Cons by Stage of Change for the HCP behavior.

Significant group differences among Stages of Change were found for Cons $F(3, 194)= 7.87, p<.001, \eta^2= .109$. Post hoc analyses using Tukey HSD tests indicated participants in Precontemplation ($M= 61.59, SD= 11.02$) rated Cons significantly higher than those in Preparation ($M= 50.55, SD= 9.64$), $p=.040$, and Action/Maintenance ($M= 48.01, SD= 9.69$), $p=.004$. In addition, participants in Contemplation ($M= 56.10, SD= 7.99$) rated Cons significantly higher than those in Action/Maintenance, $p=.001$.

No significant group differences among Stages of Change for naming a HCP were found for age, race, gender, Relationship, Communication Life Experience, and AVCB.

Interventions. Significant group differences among Stages of Change for talking to the loved one about end-of-life care interventions were found for Pros $F(3, 210)= 7.17, p<.001, \eta^2= .093$. Post hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 41.53, SD= 8.45$) rated Pros significantly lower than those in Preparation ($M= 50.79, SD= 9.84$), $p= .017$, and Action/Maintenance ($M= 51.32, SD= 9.28$), $p= .003$. In addition, participants in Contemplation ($M= 43.30, SD= 12.31$) rated Pros significantly lower than those in Preparation ($M= 50.79, SD= 9.84$), $p= .042$, and Action/Maintenance, $p=.007$.

Significant group differences among Stages of Change were found for Cons $F(3, 194)= 7.87, p<.001, \eta^2= .109$. Post Hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 64.70, SD= 9.01$) rated Cons significantly higher than those in Preparation ($M= 50.54, SD= 8.19$) and Action/Maintenance ($M= 48.01, SD= 9.24$), both $p< .001$. In addition, participants in Contemplation ($M= 58.64,$

$SD= 9.08$) rated Cons significantly higher than those in Preparation ($M= 50.54$, $SD= 8.19$), $p= .029$, and Action/Maintenance, $p< .001$. Table 8 shows the ANOVA results for surrogate ratings on Pros and Cons by Stage of Change for the Interventions behavior.

No significant group differences among Stages of Change for talking to the loved one about end-of-life care interventions were found for age, race, gender, Relationship, Communication, Life Experience, and AVCB.

Quality versus Quantity of Life. Significant group differences among Stages of Change for talking to the loved one about quality versus quantity of life were found for Pros $F(3, 207)= 6.25$, $p<001$, $\eta^2= .083$. Post hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 41.02$, $SD= 7.76$) rated Pros significantly lower than those in Preparation ($M= 50.91$, $SD= 9.80$), $p= .010$, and Action/Maintenance ($M= 51.15$, $SD= 9.55$), $p= .002$. In addition, participants in Contemplation ($M= 44.53$, $SD= 11.64$) rated Pros significantly lower than those in Action/Maintenance, $p=.048$.

Significant group differences among Stages of Change were found for Cons $F(3, 194)= 19.75$, $p<001$, $\eta^2= .234$. Post hoc analyses using Tukey HSD tests indicated that participants in Precontemplation ($M= 68.35$, $SD= 4.42$) rated Cons significantly higher than those in Contemplation ($M= 57.67$, $SD= 8.83$), $p= .024$, Preparation ($M= 50.94$, $SD= 10.20$), $p< .001$, and Action/Maintenance ($M= 47.81$, $SD= 8.72$), $p< .001$. In addition, participants in Contemplation rated Cons significantly higher than those in Action/Maintenance, $p< .001$. Table 9 shows the

ANOVA results for surrogate ratings on Pros and Cons by Stage of Change for the Quality versus Quantity of Life behavior.

No significant group differences among Stages of Change were found for age, race, gender, Relationship, Communication Life Experience, and AVCB in the Quality versus Quantity of Life behavior.

Multiple Regressions. Standard multiple regressions were run to examine possible relationships between predictors and Stage of Change in each of the four ACP behaviors. Only predictors that showed significant differences among Stage of Change in each of the four ACP behaviors were entered into the regression models.

Living Will. A multiple regression was run including Pros, Cons, and AVCB as predictors and Living Will ACP Stage of Change as the dependent variable. Cons accounted for 23% of the variance, $R^2 = .23$, $F(3, 185) = 18.181$, $p < .001$, and was found to be the only significant predictor of Living Will Stage of Change, $\beta = -.49$, $t(188) = -6.53$, $p < .001$, indicating a significant negative relationship between Cons and surrogate Stage of Change in the Living Will behavior.

HCP. A multiple regression was run including Pros and Cons as predictors and HCP Stage of Change as the dependent variable. Cons accounted for 10% of the variance, $R^2 = .10$ [$F(2, 195) = 11.24$, $p < .001$], and was the only significant predictor for Stage of Change $\beta = -.32$, $t(197) = -4.11$, $p < .001$, indicating a negative relationship between Cons and surrogate Stage of Change in the HCP behavior.

Interventions. A multiple regression was run including Pros, and Cons as predictors and Interventions Stage of Change as the dependent variable. Cons accounted for 19% of the variance, $R^2 = .19$, $F(2, 196) = 22.58$, $p < .001$, and was the

only significant predictor for Stage of Change $\beta = -.38$, $t(198) = -5.09$, $p < .001$, indicating a significant negative relationship between Cons and surrogate Stage of Change in the Interventions behavior.

Quality versus Quantity of Life. A multiple regression was run including Pros and Cons as predictors and Quality vs. Quantity of Life Stage of Change as the dependent variable. Cons accounted for 22% of the variance, $R^2 = .22$ [$F(2, 195) = 27.18$, $p < .001$] indicating a significant negative relationship, $\beta = -.46$, $t(197) 6.28$, $p < .001$, with surrogate Stage of Change in the Quality vs. Quantity of Life behavior. Table 10 provides a summary of the multiple regression results for each of the four ACP behaviors.

Hypothesis II: Exploratory Analyses of Surrogate-Older Patient

Discrepancy

Method

In this set of analyses, factors associated with the Discrepancy between older patients and their surrogates Stage of Change within each of the four ACP behavior staging algorithms are evaluated. A series of one-way Analysis of Variance (ANOVA) models were used to compare differences in Discrepancy between surrogate-older patient Stage of Change in each of the four ACP algorithms among race, gender, Relationship, and Communication groups in each of the four ACP algorithms. Correlations compared relationships with discrepancy and continuous variables, which include age, Life Experience, Pros, Cons, and AVCB and Discrepancy (i.e. levels of agreement) on Stages of Change in each of the four algorithms. In addition, Stage of

Change distribution in the surrogate and older patients was evaluated in order to examine patterns in overall readiness to complete each of the four ACP behaviors.

Results

As illustrated in Figure 2, across the four ACP behaviors, older patients reported being less ready to complete ACP behaviors than the surrogate sample. For example, comparison of Stage of Change distribution across the two samples in the HCP behavior shows that more older patients were in Precontemplation (31.3%) and Contemplation (7.6%), whereas more surrogates were in Preparation (15.4%) and Action/Maintenance (23.7%). In addition to notable differences in the level of readiness in the two groups, the overall distribution of Stage of Change shows that the majority of participants are in Action/Maintenance, with the exception of older patients in the HCP behavior.

Living Will. A significant positive correlation was found between Discrepancy in the Living Will behavior and age, $r(215) = .14, p = .040$. No significant correlations were found between Pros, Cons, and AVCB and Discrepancy. In addition, no significant differences on Discrepancy were observed amongst, race, gender, Relationship, and Communication in the Living Will behavior.

HCP. No significant correlations between age, Life Experience, Pros, Cons, and AVCB, and Discrepancy on Stage of Change in the HCP behavior were found. In addition, no significant differences on Discrepancy were observed amongst race, gender, Relationship, and Communication groups in the HCP behavior

Interventions. A significant negative correlation was observed between surrogate ratings on Pros and Discrepancy in the Intervention behavior, $r(207) = -$

.56, $p < .001$. A significant positive correlation was observed between surrogate ratings on Cons and Discrepancy, $r(194) = .25$, $p = .001$. In addition, a significant positive correlation was found between Discrepancy and AVCB, $r(193) = .31$, $p < .001$, in the Interventions behavior.

Significant group differences among gender groups were found in Discrepancy on Stage of Change in the Interventions behavior, $F(1, 208) = 5.95$, $p = .016$, $\eta^2 = .028$. Table 11 shows the ANOVA results for gender group differences on Discrepancy of Stage of Change in Interventions.

Surrogate age and Life Experience were not significantly correlated with Discrepancy on Stage of Change in the Interventions behavior. In addition, no significant group differences among race, Relationship, and Communication were found on Discrepancy.

Quality vs. Quantity of Life. A significant negative correlation was observed between surrogate ratings on Cons and Discrepancy, $r(188) = -.22$, $p = .002$.

Age, Life Experience, Pros, and AVCB were not significantly correlated with Discrepancy in the Quality versus Quantity of Life behavior. In addition, no significant group differences among race, gender, Relationship, and Communication were found on Discrepancy. Table 12 includes correlations between the continuous independent variables and surrogate- older patient Discrepancy in readiness to complete each of the four ACP behaviors.

Discussion

Surrogate Readiness to Help a Loved One in ACP Behaviors

Medical interventions have the potential to prolong life far beyond the point at which an individual would live in the absence of these interventions. Given that medical interventions can be costly and often exceed the amount of care a patient would wish to receive at end-of-life (Zhang, 2009), it is important that all involved in end-of-life care decision making fully understand the patient's wishes through the following ACP behaviors: completing a living will that documents end-of-life wishes (Living Will), appointing a health care proxy (HCP), discussing the use of interventions with loved ones (Interventions), and discussing quality versus quantity of life with loved ones (Quality versus Quantity of Life). Studies have found that the amount of individuals who have completed ACP is insufficient, and further, those who have completed a living will and HCP often have insufficient communication with loved ones regarding their end-of-life wishes, which often leads to discordant end-of-life care.

In order to further explore this issue, the present study examined predictors associated with surrogate readiness to help a loved one in doing the four ACP behaviors. The overall results did not support the hypothesis that age, race, gender, Life Experience, Relationship, Communication, Pros, and AVCB would be significant predictors of Stage of Change in all of the ACP behaviors. However, exploratory analyses revealed that Pros, Cons, and AVCB were significantly associated with Stage of Change in the Living Will behavior. Higher ratings on Pros was associated with more surrogate readiness to help a loved one complete a living will document,

whereas higher ratings on Cons and AVCB was associated with less surrogate readiness to help a loved one complete a Living Will. Additionally, in the ACP behaviors, HCP, Interventions, and Quality versus Quantity of Life, significant differences were found among Stages of Change in Pros and Cons. In each of these behaviors, higher ratings on Pros was associated with more surrogate readiness to help a loved one complete HCP, discuss the use of end of life interventions as well as focus on quality versus quantity of life with their loved one. Conversely, higher ratings on Cons was associated with less readiness to help a loved one complete HCP, and discuss the use of interventions as well as quality versus quantity of life with their loved one. The association between increased Pros and greater surrogate readiness, as well as the association between increased Cons and less surrogate readiness is consistent with the relationships between Pros and Cons, and Stage of Change in the older patient sample (Fried et al., 2012).

A significant predictor in each surrogate ACP behavior was Cons, or perceived negative consequences of a given ACP behavior. These findings indicate that lower ratings of Cons is associated with helping a loved one in each of the four ACP behaviors. In other words, surrogates who perceived fewer negative consequences to performing ACP were more ready to help an older patient (i.e. loved one) complete and discuss ACP behaviors. This finding is consistent with previous research that suggesting that ACP non-completers were more concerned with negative beliefs associated with ACP (e.g. “advanced directives are too binding”) than ACP completers (Beck, Brown, Boles, & Barret, 2002). It may be helpful for health care providers to focus on addressing the negative aspects or Cons of ACP in their

consultations with patients and their loved ones, thus promoting more surrogate involvement in the ACP process. This is consistent with implications of the patient perceived barriers to ACP examined by Schickedanz and colleagues (2009). This finding is not consistent with previous TTM research across many behavioral domains, which suggests that Pros are more strongly associated with readiness for behavior change than are Cons (Hall & Rossi, 2008). Results from Schickedanz and colleagues (2009) suggested six barrier themes that impeded patients from completing ACP behaviors, which include the following: “perceiving ACP as irrelevant (84%); personal barriers (53%); relationship concerns (46%); information needs (36%); health encounter time constraints (29%), and problems with advance directives (29%). Some barriers were endorsed at all steps (e.g., perceiving ACP as irrelevant). Others were endorsed at individual steps (e.g., relationship concerns for family/friend discussions, time constraints for doctor discussions, and problems with advance directives for documentation)” (p. 5). Schickedanz and colleagues (2009) drew conclusions similar to the present study regarding the importance for health care providers to address barriers or perceived negative consequences of completing ACP behaviors. This finding may have significant implications for the development of future intervention programs in medical care settings.

Agreement on Readiness to Complete ACP Behaviors

Research suggests that insufficient communication between the older patient and their surrogate often leads to end-of-life care that is discordant with patient wishes (Shalowitz et al., 2006; Torke, Moloney, Siegler, Abalos, & Alexander, 2010). Given that little is known regarding the factors that may contribute to this discordance, this

set of analyses aimed to examine surrogate variables that may be associated with the level of discrepancy among older patient-surrogate Stages of Change in each of the four ACP behaviors. The difference in overall Stage of Change distribution between the surrogates and older patients suggests that surrogates may be more willing to participate in ACP behaviors than older patients. This implies that involving loved ones in the ACP process may encourage older patients to complete ACP behaviors. In comparison to other ACP behaviors, Stage of Change distributions suggest that older patients may experience more difficulty in appointing an HCP, which further implicates the importance of older patient communication with loved ones regarding end-of-life care wishes. Reasons why these patterns of readiness are observed may be elucidated in future research. These findings may also have implications for clinical discussions.

Results indicated that age was significantly associated with Discrepancy in surrogate-older patient Stage of Change in the Living Will behavior. More specifically, older surrogates were more likely to have discordance with their loved one in readiness to complete a living will. Given that the strength of this association was relatively weak, this result should be interpreted with caution. No surrogate variables were found to be significantly associated with Discrepancy in readiness to complete the HCP behavior.

In terms of Discrepancy on Stage of Change in the Interventions behavior, results indicated that higher ratings on Pros was associated with more surrogate-older patient agreement, whereas higher ratings of Cons and AVCB was associated with less surrogate-older patient agreement. In addition, results indicate that female surrogates

were more likely to be on the same level of readiness as their loved ones to discuss the use of medical interventions at end-of-life care than male surrogates. Pros was significantly associated with Discrepancy between surrogate and older patient Stage of Change in Interventions, which suggests that surrogates who perceive more positive consequences related to discussing medical interventions at end-of-life care were more likely to be at the same level of readiness as their loved one to complete this behavior.

Surrogate ratings on Cons was significantly correlated with Discrepancy on Stages of Change in the Quality versus Quantity of Life behavior, indicating that surrogates who endorsed more perceived negative consequences of completing the Quality versus Quantity of Life behavior were more likely to be on the same level of readiness as their loved ones. Overall, results suggest that it may be helpful to address perceived positive and negative aspects of ACP, as well as cultural beliefs that may play a role in older persons' readiness to communicate medical wishes with their loved ones. However, given that these results are mixed, they should be interpreted with caution.

Limitations

An important limitation of the present study is that the later Stages of Change are over-represented in the surrogate sample in each of the ACP behaviors, with the majority (i.e. $\geq 58\%$) of participants in the Action/Maintenance Stage of Change and a small portion (i.e. $< 8\%$) in the Precontemplation Stage of Change. This over-representation of later Stages of Change suggests that the present sample may represent a subset of the general population of older persons and their loved ones, thus the present findings may be limited in generalizability. Further, cross-sectional data is

limiting with regard to understanding behavior change; therefore, results from the present data can only indicate which factors may be relevant in longitudinal studies.

Although the scales utilized in the surrogate sample were validated in the older patient sample (Fried et al. 2012), confirmatory factor analysis has not been performed on these scales in the surrogate sample. Thus, the present results involving the Decisional Balance and AVCB measures should be interpreted with caution. In addition, the present study only examined predictor variables derived from the surrogate sample. Examining variables from the older patient sample may provide more information regarding predictors of surrogate Stage of Change as well as Discrepancy on Stages of Change.

Another limitation in the present study is that the Discrepancy measure merely reveals discordance between the surrogate and older patient Stage of Change in each ACP behavior. This measure does not describe the nature of the discordance; therefore, conclusions derived from this measure are limited. For example, although a surrogate-older patient pair may have Optimal Agreement in the Precontemplation Stage of Change, this level of agreement holds different implications than a pair in the Action/Maintenance Stage of Change of a given ACP behavior.

Future Directions

As the data in the present study are cross-sectional, longitudinal data would add more information regarding the longevity of a TTM intervention in ACP behaviors and surrogate readiness to assist their loved ones in the process. TTM data on ACP support between patients and surrogates assessed at multiple time points is a future goal for this research.

This study indicates that Cons, or perceived negative aspects of helping a loved one in the ACP process, can influence a surrogate's readiness to participate in the process. Therefore, it may be important for future studies to work toward better understanding effective ways to address these perceived negative consequences or barriers in order to promote surrogate's helping loved ones in the ACP process. Schickedanz and colleagues (2009) examined barriers in contemplation, communication, and documentation ACP behaviors in an old patient sample and identified 20 self-reported barriers associated with ACP completion. These barriers included 6 themes: perception of ACP as irrelevant, personal barriers, relationship concerns, information needs, health encounter time, constraints, and problems with advance directives. These barriers are similar to some Cons in the present study; however, the findings in the Schickedanz and colleagues (2009) study suggests that this list may be limited. In future research, it may be beneficial to examine the barriers identified by Schickedanz and colleagues (2009) as potential predictors of surrogate Stage of Change in the four ACP behaviors in the present study. This research would further help physicians understand the potential barriers to ACP that may be important to address in their consultations with older patients and their surrogates.

Given that previous experiences in medical decision making has been identified as a factor that may increase a surrogate's willingness to help a loved one in ACP (Vig et al., 2007) it may be beneficial to develop a valid and reliable measure of medical decision-making experience in a surrogate sample. This may provide more information regarding the importance of this factor in surrogate involvement in ACP.

Future research needs to further examine gender differences in surrogates' communication behaviors with older loved ones. This may uncover factors related to the finding that female surrogates had significantly higher concordance with their loved one in readiness to discuss the use of interventions at end-of-life. Future studies examining gender differences in ACP communication behaviors may help health care providers better understand different communication styles or techniques that work best for each gender in the context of end-of-life care planning.

Surrogates in the present study were unevenly distributed amongst the Stages of Change in each ACP behavior and there were very few participants in the earlier Stages of Change (i.e. ≤ 17). Given that the Stages of Change were not equally represented and Precontemplation was underrepresented in the surrogate sample, it may be beneficial to recruit a larger sample that more fully reflects the range of readiness for ACP behaviors in future studies. This would add more power to the results overall and would allow researchers to draw more reliable conclusions. In addition, future research should utilize the TTM-tailored interventions aimed to improve readiness to complete ACP behaviors or assist a loved one in completing these behaviors. Longitudinal data should be collected at multiple time points in order to assess the efficacy of the intervention.

The present study only examined independent variables derived from the surrogate sample; therefore, future studies may want to examine independent variables from the older patient sample as well. Future research could examine relationships between older patient independent variables and surrogate Stages of Change. In addition, it may be important to examine independent variables from the older patient

sample as predictors of older patient and surrogate Discrepancy on Stage of Change in each behavior. This research may provide more valuable information aimed to guide health care provider discussions with patients and their loved ones regarding ACP.

Given that the Discrepancy measure provides limited information regarding surrogate-older patient discordance on readiness to complete ACP behaviors, it may be beneficial to develop a measure that more accurately describes the nature of the surrogate-older patient discordance and elucidate more reasons why a discrepancy may exist on readiness to complete ACP behaviors.

It is important that future research address ways to promote communication between all involved in end-of-life care planning in order to improve the quality of health care services. A recent report by the Institute of Medicine (2014) highlights the growing need for research that can effect change in policy in order to expand the availability and improve the effectiveness of medical and social services for patients and their families. This report suggests that research in this area has made recent gains by identifying the utility of communication technology and recognizing the importance of family and caregivers in the decision making process; however, there remains a need for a more patient and family-centered approach to this issue in health care settings (Institute of Medicine, 2014). Therefore, future research aimed to further improve individually tailored interventions in ACP is needed to bridge the gap between research and policy and improve the quality of end-of-life care.

Table 1
Demographic Variables for Old Patient and Surrogate Samples

Old Patient Demographics		
	<u>M</u>	<u>SD</u>
Age	75	7
	<u>N</u>	<u>%</u>
Gender		
Female	222	73
Male	82	27
Race		
White	225	74
Nonwhite	79	26
Surrogate Demographics		
	<u>M</u>	<u>SD</u>
Age	60	13
	<u>N</u>	<u>%</u>
Gender		
Female	148	68
Male	70	32
Race		
White	151	69
Non-white	67	31
Relationship		
Spouse	88	40
Child	92	42
Other	38	18
Communication		
Daily	167	76
Weekly or less	51	24

Note. *M*= mean; *N*= sample size; *SD*=standard deviation

Table 2

Frequencies for Stages of Change and Percentage Differences Between Surrogate and Older Patient Stage of Change in Each of the Four ACP Behaviors

ACP Behavior	Stage of Change	Surrogates		Older Patients		Surrogate-Older Patient % Difference
		N	Valid%	N	Valid%	
Living Will	PC	17	7.8	79	26	18.2
	C	34	15.7	55	18.1	2.4
	PR	41	18.9	15	4.9	14
	A/M	125	57.6	155	51	6.6
HCP	PC	11	5.1	110	36.4	31.3
	C	28	12.9	62	20.5	7.6
	PR	52	24	26	8.6	15.4
	A/M	126	58.1	104	34.4	23.7
Interventions	PC	14	6.5	75	25.3	18.8
	C	18	8.3	26	8.8	0.5
	PR	35	16.1	15	5.1	11
	A/M	150	69.1	180	60.8	8.3
Quality vs. Quantity of Life	PC	14	6.5	114	38.6	32.1
	C	17	7.9	30	10.2	2.3
	PR	35	16.4	8	2.7	13.7
	A/M	148	69.2	143	48.5	20.7

Note. HCP= health care proxy; all percentages are presented as absolute values

Table 3

Descriptive Statistics for the Level of Discrepancy Between Surrogate and Older Patient Stages of Change in Four ACP Behaviors

<u>ACP Behaviors</u>	<u>N</u>	<u>Min</u>	<u>Max</u>	<u>M</u>	<u>SD</u>
Living Will	217	0.00	3.00	1.41	1.14
HCP	215	0.00	3.00	1.53	1.10
Interventions	210	0.00	3.00	1.18	1.23
Quality vs. Quantity of Life	205	0.00	3.00	1.80	1.23

Note. HCP= health care proxy; *M*= mean; *N*= sample size; *SD*=standard deviation

Table 4

Cronbach's Alphas for Life Experience, AVCB, and Pros and Cons

<u>Measure</u>	<u>Min</u>	<u>Max</u>	<u>M</u>	<u>SD</u>	<u># of items</u>	<u>α</u>
Life Experience	6	12	9.86	1.48	6	0.48
AVCB	7	28	10.70	3.68	7	0.86
Pros	14	30	27.04	3.04	6	0.88
Cons	6	29	11.95	4.93	6	0.84

Note. *SD*= standard deviation; *M*= mean; α = Chronbach's alpha AVCB= attitudes, values, and cultural beliefs

Table 5

Correlations Amongst Surrogate Pros, Cons, AVCB, and Life Experience

<u>Pros</u>	<u>Pros</u>	<u>Cons</u>	<u>AVCB</u>
<u>Cons</u>	--	--	
<u>AVCB</u>	-0.46**	.44**	--
<u>Life Experience</u>	-.48*	0.1	0.04

Note: ** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed); T-scores for Pros, Cons, and AVCB were used in analyses; AVCB= attitudes, values, and cultural beliefs.

Table 6

ANOVAs between Living Will Stages of Change on Pros, Cons, and AVCB

Measures	<i>df</i>	<i>F</i>	η^2	<i>p</i>
Pros	3	8.99	.114	<.001**
Cons	3	22.13	.225	<.001**
AVCB	3	3.34	.049	.020*

Note. * $p < .05$; ** $p < .01$; AVCB= attitudes, values, and cultural beliefs

Table 7
ANOVAs between HCP Stages of Change on Pros and Cons

Measures	<i>df</i>	<i>F</i>	η^2	<i>p</i>
Pros	3	8.99	.114	.003**
Cons	3	22.13	.225	<.001**

Note. * $p < .05$; ** $p < .01$

Table 8

ANOVAs between Interventions Stages of Change on Pros and Cons

Measures	<i>df</i>	<i>F</i>	η^2	<i>p</i>
Pros	3	7.17	.093	<.001**
Cons	3	15.36	.191	<.001**

Note. * $p < .05$; ** $p < .01$

Table 9

ANOVAs between Quality versus Quantity of Life Stages of Change on Pros and Cons

Measures	<i>df</i>	<i>F</i>	η^2	<i>p</i>
Pros	3	6.25	.083	<.001**
Cons	3	19.75	.234	<.001**

Note. * $p < .05$; ** $p < .01$

Table 10

Summary of Multiple Regressions for Surrogate Stage of Change in Four ACP Behaviors

ACP Behaviors R^2	Predictors	β	t	p	CI (95%)
Living Will $R^2 = .228$	Pros	-.008	-.107	.915	-.015-.014
	Cons	-.494	-6.525	<.001**	-.060- -.032
	AVCB	.032	.420	.675	-.012- .018
HCP $R^2 = .103$	Pros	.001	.009	.993	-.013- .013
	Cons	-.321	-4.112	<.001**	-.039- -.014
Interventions $R^2 = .187$	Pros	.096	1.288	.199	-.004- .020
	Cons	.377	-5.085	<.001**	-.044- -.019
Quality versus Quantity of Life $R^2 = .218$	Pros	.017	.236	.814	-.011- .013
	Cons	-.458	-6.275	<.001**	-.049- -.026

Note. ** $p < .01$; * $p < .05$; β = standardized coefficient; CI = confidence interval; HCP= health care proxy

Table 11
ANOVA for Gender on Surrogate-Older Patient Discrepancy on Stage of Change in the Interventions Behavior

Surrogate Variable	<i>df</i>	<i>F</i>	η^2	<i>p</i>
Gender	1	5.95	.028	.016*

Note. * $p < .05$; ** $p < .01$

Table 12

Correlations Between Continuous Surrogate Variables and Surrogate- Older Patient Discrepancy in Readiness to Complete Four ACP Behaviors

Surrogate Variables	Living Will	HCP	Interventions	Quality vs. Quantity of Life
Age	.140*	.077	.111	.010
Life Experience	-.115	-.022	.121	.030
Pros	-.026	-.033	-.559**	-.080
Cons	.035	-.092	.246**	-.218**
AVCB	.050	.075	.307**	-.043

Note. **Correlation is significant at the .01 level (2-tailed); *Correlation is significant at the .05 level (2-tailed); HCP= health care proxy; AVCB= attitudes, values, and cultural beliefs.

Figure 1. Pros, Cons, and AVCB by Surrogate Stage of Change in Four ACP Behaviors

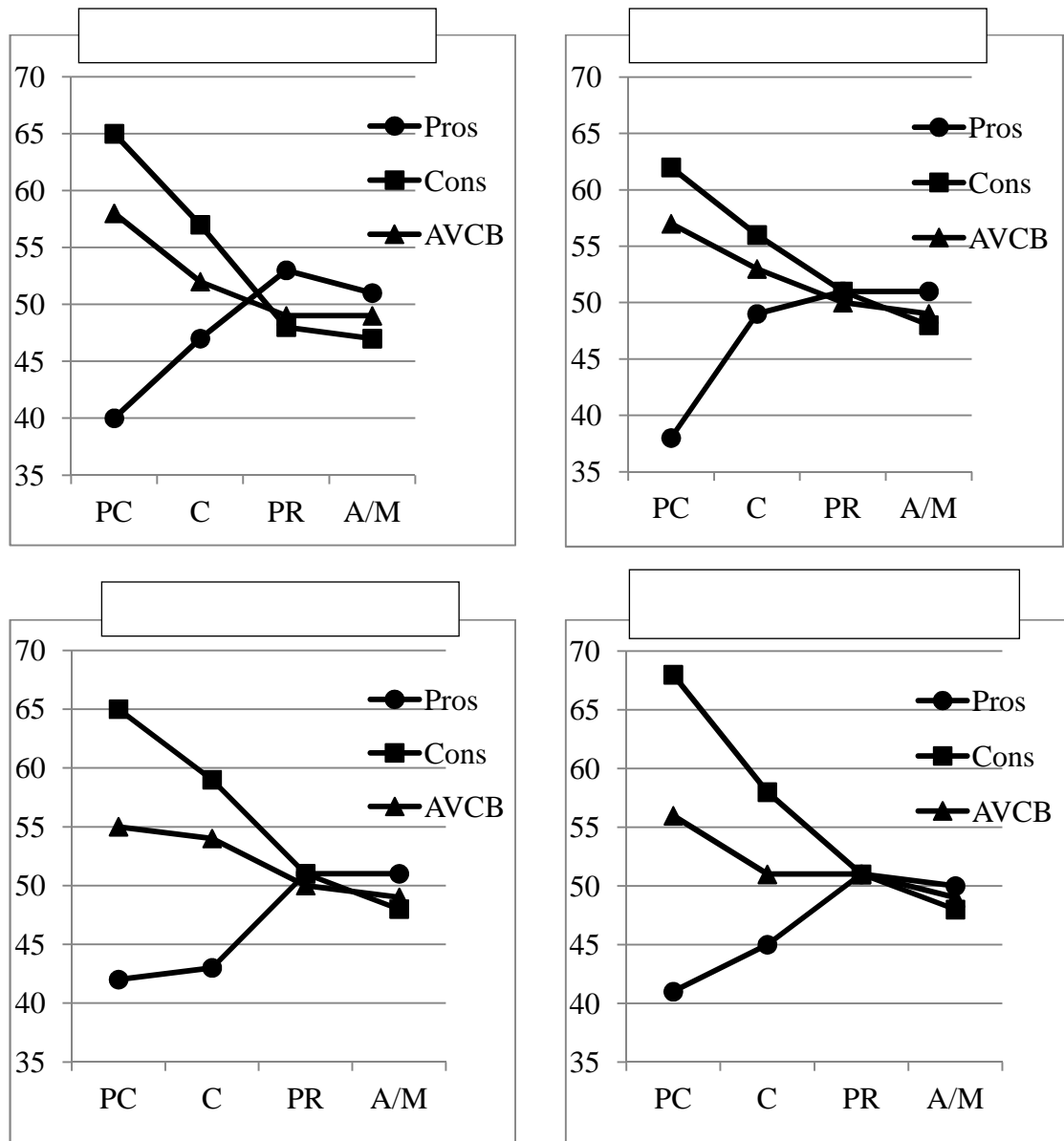


Figure 1. Line graph showing the distribution of mean T-scores of Pros, Cons, and AVCB across Stage of Change in four ACP behaviors. Stages of Change include Precontemplation (PC), Contemplation (C), Preparation (PR), Action/Maintenance (A/M).

Figure 2. Percentages of Surrogate and Older Patient Stage of Change in Four ACP Behaviors

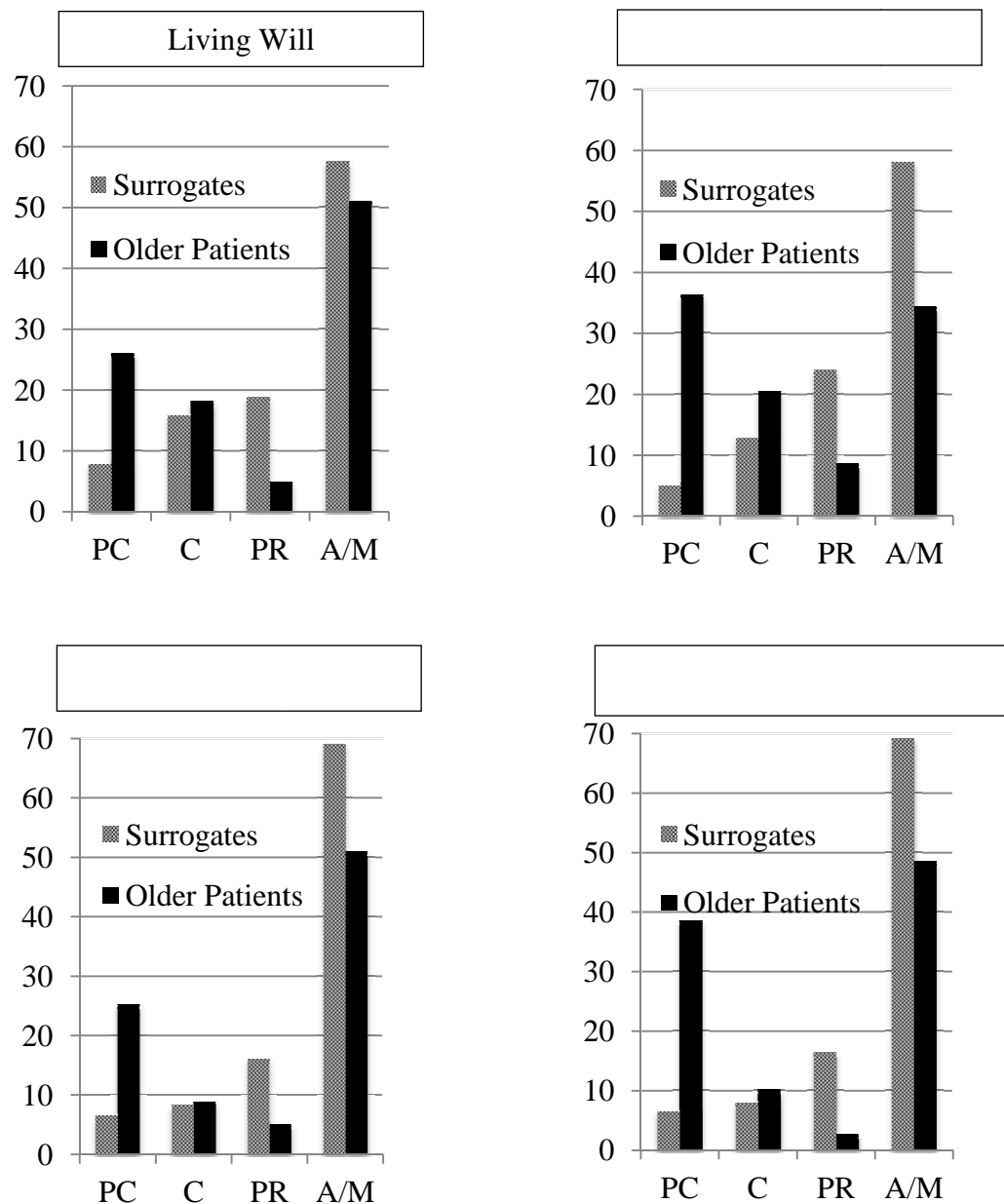


Figure 2. Bar graph showing the percentages of surrogates and older patients in each Stage of Change in four ACP behaviors. Stages of Change include Precontemplation (PC), Contemplation (C), Preparation (PR), Action/Maintenance (A/M).

Appendices A-D

A. LIFE EXPERIENCE

- | | | | |
|----|--|-----|-----|
| 1. | Have you ever faced a life-threatening illness? | Yes | - 1 |
| | | No | - 2 |
| 2. | Have you ever had a risky or major surgery? | Yes | - 1 |
| | | No | - 2 |
| 3. | Have you ever had to make a medical decision for someone who was dying? | Yes | - 1 |
| | | No | - 2 |
| 4. | Have you ever known someone who you believe had a bad death because he/she received too much medical care? | Yes | - 1 |
| | | No | - 2 |
| 5. | Have you ever known someone who you believe had a bad death because he/she received too little medical care? | Yes | - 1 |
| | | No | - 2 |
| 6. | Have you experienced the death of a loved one who made his/her wishes about end-of-life care known? | Yes | - 1 |
| | | No | - 2 |

B. ADVANCE CARE PLANNING - PROS AND CONS

Let us take a moment to review what advanced care planning Consists of: 1) Living Will, 2) Health Care Proxy, 3) Talking to your loved ones and doctor about medical care you do or do not want to receive at the end-of-life.

Here are some possible advantages and disadvantages of planning for your future medical care in the ways that I just asked you about. Please tell me how much you agree or disagree with these statements. Please choose your answer from a scale of 1 to 5, where 1 means strongly agree, 2 means agree, 3 means neither agree nor disagree, 4 means disagree and 5 means strongly disagree. Now, some of these questions may not be clear to you, if so please respond with “I do not understand the question” as your response.

<u>How strongly do I agree that?</u>	Strongly Agree	Agree	Agree nor Disagree	Disagree	Strongly Disagree	Doesn't Understand Question
2. It would be hard to help my loved one do advanced care planning because I don't like thinking about him/her being very ill.	1	2	3	4	5	9
6. I don't want to talk with my loved one about end-of-life decisions.	1	2	3	4	5	9
8. It would be hard to help my loved one do advanced care planning because there are too many options to Consider for my loved one's end of life care.	1	2	3	4	5	9
11. Understanding my loved one's wishes would help me to ensure he/she would get the care he/she wants.	1	2	3	4	5	9

ADVANCE CARE PLANNING - PROS AND CONS (Continued)

12.	I would feel better knowing my loved one has done what he/she can to plan for his/her future.	1	2	3	4	5	9
14.	Doing advanced care planning would make sure that my loved one got the kind of end of life care he/she wants.	1	2	3	4	5	9
15.	My loved one does not want to talk about his/her end of life care.	1	2	3	4	5	9
16.	I would feel better knowing my loved one is making his/her wishes clear for the future.	1	2	3	4	5	9
17.	Helping my loved one do advanced care planning would go against his/her lifestyle of taking one day at a time.	1	2	3	4	5	9
18.	Helping my loved one do advanced care planning would give me peace of mind.	1	2	3	4	5	9
23.	It would be too hard on my loved one to plan for his/her future care.	1	2	3	4	5	9
24.	Advanced care planning would help my loved one to keep control over what happens to him/her at the end of life.	1	2	3	4	5	9

C. ADVANCE CARE PLANNING- ATTITUDES VALUES AND BELIEFS

Here are some additional beliefs about issues related to advance care planning. Please tell me how strongly you agree with the following statements, continuing to use the same answer categories. Now, some of these questions may not be clear to you so please respond with “I do not understand the question” as your response.

How strongly do I agree that:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Doesn't Understand Question
3. My loved one doesn't need advance care planning because once you reach a certain age, doctors aren't going to use machines.	1	2	3	4	5	9
4. My loved one does not need to do advance care planning because once it becomes clear that you are dying, the doctors aren't going to use machines.	1	2	3	4	5	9
5. My loved one does not need to do advance care planning because his/her doctor knows what he/she wants for end of life care.	1	2	3	4	5	9
7. My loved one does not need to do advance care planning because he/she is most likely not going to face any hard health care decisions.	1	2	3	4	5	9
8. My loved one does not need to do advance care planning because he/she will always be able to make his/her own treatment decisions when the time comes.	1	2	3	4	5	9
9. Advance care planning would interfere with the plans that the Lord has for my loved one.	1	2	3	4	5	9
12. Planning future medical care only makes sense for those who are much older or sicker than my loved one	1	2	3	4	5	9

D. STEPS FOR ADVANCED CARE PLANNING

Now we will talk about the specific steps involved in advanced care planning and what steps your loved one has taken.

1. A living will is not the same as a regular will. This is a piece of paper that generally includes a statement saying that if a person's condition is thought to be terminal or if the person is permanently unconscious, then the person should not be kept alive through life support systems.

Has your loved one made out a living will?	GO TO Q. 2 ←Yes	- 1
	GO TO Q. 1b ←No	- 2
	Don't know	- 8

- 1a. Are you ready to ask your loved one if he/she has a living will?

Yes	- 1
GO TO Q.2 ←No	- 2

- 1b. How ready are you to help your loved one complete a living will (if he/she doesn't have one)?

I am not ready to help my loved one complete a living will	- 1
I am thinking about helping my loved one complete a living will in the next 6 months	- 2
I am planning to help my loved one complete a living will in the next 30 days	- 3
NA	- 9

2. Naming a health care proxy means that you have decided on the person you want to make medical decisions for you if you cannot make them yourself and filling out a form saying that this person is your choice.

Has your loved one named a health care proxy?	GO TO Q. 3 ←Yes	- 1
	GO TO Q. 2b ← No	- 2
	Don't know	- 8

STEPS FOR ADVANCED CARE PLANNING (Continued)

- 2a. Are you ready to ask your loved one if he/she has a health care proxy? Yes - 1
- GO TO Q. 3 ←No** - 2
- 2b. How ready are you to help name your loved one to name a health care proxy (if he/she hasn't named one)?
- I am not ready to help my loved one name a health care proxy - 1
- I am thinking about helping my loved one name a health care proxy in the next 6 months - 2
- I am planning to help my loved one name a health care proxy in the next 30 days - 3
- NA - 9
3. Are you aware that when people get sick, there are machines that can be used to keep them alive, such as a breathing machine?
- Yes - 1
- GO TO Q.4 ←No** - 2
- 3a. Have you ever talked with your loved one about whether he/she would want to be kept alive on a machine if he/she was very sick?
- GO TO Q. 4 ←Yes** - 1
- No - 2
- 3b. How ready are you to talk to your loved one about this situation?
- I am not ready to help my loved one name a health care proxy - 1
- I am thinking about helping my loved one name a health care proxy in the next 6 months - 2
- I am planning to help my loved one name a health care proxy in the next 30 days - 3
- NA - 9

STEPS FOR ADVANCED CARE PLANNING (Continued)

4. Are you aware that some people do not want to live as long as possible if they have a poor quality of life?
- | | |
|--|-----|
| Yes | - 1 |
| GO TO NEXT PAGE, PROS AND CONS ← No | - 2 |
- 4a. Have you ever talked with your loved one about whether he/she would want to live as long as possible if he/she had a poor quality of life?
- | | |
|------------------------------|-----|
| GO TO NEXT PAGE ← Yes | - 1 |
| No | - 2 |
- 4b. How ready are you to talk to your loved one about this situation?
- | | |
|---|-----|
| I am not ready to talk to my loved one about this situation | - 1 |
| I am thinking about in the next 6 months | - 2 |
| I am planning to in the next 30 days | - 3 |
| NA | - 9 |

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